Testimony of Brittany Gancarz, Certified Genetic Counselor at UConn Health in support of SB857-An Act Concerning Licensure for Genetic Counselors February 20, 2015

Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan and members of the Public Health Committee, my name is Brittany Gancarz and I am here to testify in strong support of Senate Bill 857- An Act Concerning Licensure for Genetic Counselors.

I have been practicing as a genetic counselor for approximately two and a half years, and during that time I have worked at UConn Health Center in Farmington, seeing patients in the Maternal-Fetal Medicine Department. I am a native of Connecticut, originally from Shelton, and currently live in Colchester.

As a prenatal counselor, I review options for prenatal testing to expectant parents. I explain the availability of these tests, the risks and benefits, and inform them what sort of information they could receive from having genetic testing in their pregnancy. I go through an informed consent process with patients to ensure that they desire genetic testing, and understand both the value and the limitations of the testing they have. When there is a family history of a genetic condition, I may meet with a couple prior to pregnancy to discuss the risks for their children, or during pregnancy to facilitate prenatal testing, if they desire. I may also meet with a family following a birth defect seen in pregnancy. For the patients I see, I facilitate any genetic testing they may have, ensuring that the appropriate test is ordered, and the patient and other providers are educated about the tests and the results. Additionally, I make every attempt to provide care that is supportive and individualized to the needs of each family, supporting them in medical, social, and emotional aspects. In slightly over two years, I have seen over 1400 patients.

Prenatal genetic testing has rapidly expanded within the past several years. New tests have become available in the past two years, and those tests have undergone significant changes from the time they first became available to the public until now. The most significant of these developments has been the introduction of non-invasive prenatal testing, a blood test that a pregnant woman can have that can predict with significant accuracy whether her baby will have Down syndrome or several other genetic conditions. Though prenatal screening for Down syndrome has been available for many years, the accuracy of this new testing has not been seen in screening tests before. Yet although this is powerful technology, this new blood test is not diagnostic, and confirmatory testing is needed when the test indicates a fetus is affected with a condition. Noninvasive prenatal testing has recently been highly criticized in the popular media, namely a Boston Globe Article in December 2014 captioned: Oversold and Unregulated Prenatal Tests Leading to Abortions of Healthy Fetuses. Misinterpretation of these test results can lead to irreversible and life-changing decisions. My colleagues and I are aware of this happening in our state when genetic counseling services were not provided with these tests. When we facilitate this testing for patients, they receive thorough pre-test and post-test counseling so that they are fully informed, and tragedies are prevented.

Licensure of genetic counselors would ensure that only individuals who have been appropriately trained and certified can represent themselves as genetic counselors. This would protect the State and the healthcare system, in addition to protecting the people of Connecticut from

unqualified individuals giving them potentially inaccurate information. Licensure would reduce billing constraints that keep many hospitals and healthcare organizations from hiring genetic counselors, thereby increasing the public's access to genetic counseling. To speak for myself as genetic counselor, I believe that licensure will ultimately make it easier for people to access the important services we provide and help us best serve the people of Connecticut.

Thank you very much for your time and consideration.

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